

Tardive Dyskinesia (Dystonia) from Psychiatric Drugs

7–8 minutes

Jenelle's Story

as told to Douglas A. Smith



Why is this young woman using a wheelchair?: She has tardive dyskinesia - caused by psychiatric drugs.

A few years ago, Jenelle got food poisoning and was given a neuroleptic drug called Reglan (metoclopramide) to suppress vomiting. The drug gave her a movement disorder called tardive dyskinesia almost right away. Because of her strange body movements caused by the drug, she was misdiagnosed as having a psychiatric problem and given other psychiatric drugs called Thorazine, Haldol, and Xanax which worsened her physical and mental condition. The psychiatric drugs she was given that are called neuroleptics (Reglan,

Thorazine, and Haldol) damaged the parts of her nervous system responsible for motor control enough to make her dependent on a wheelchair.

Now age 23 and no longer taking psychiatric drugs, Jenelle remains a charming, intellectually sharp, articulate, and pretty young woman (prettier than she looks in photographs), so much so that despite being wheelchair-bound by her drug-induced physical disability, her husband, Greg, fell in love with her and married her in May (1999), six months before the above picture of them was taken. Pictured with them is Jenelle's trained assist dog, Kramer, who has a harness with a handle on his right side that Jenelle hangs on to so Kramer can help her get around in her wheelchair.

Jenelle's type of tardive dyskinesia is called dystonia - involuntary spasms and muscle contractions that induce abnormal movements and postures. It is a neurological movement disorder caused by damage to the part of the brain called the basal ganglia. People given psychiatric drugs like those Jenelle took often also experience permanent *dementia*, which is loss of mental or intellectual function, caused by the drugs damaging the usually more vulnerable mental functions of the brain. That doesn't seem to have happened to Jenelle. In conversation, her mind seems unaffected by the lingering effects of psychiatric drugs. However, she says when she's in school she can't retain knowledge as well as she could before she took psychiatric drugs.

Jenelle hopes for improvement in her ability to move and walk normally. However, the consensus among physicians is that tardive dyskinesia is usually if not always irreversible.

Jenelle's story is representative of those of millions of people subjected to permanent brain damage by a class of psychiatric drugs variously known as *neuroleptics*, *antipsychotics*, or *major tranquilizers*. What is so poignant about Jenelle's story are (1) She had not been depersonalized (as perceived by others) by a psychiatric diagnosis before she was given a movement disorder by a neuroleptic drug, so her movement disorder can't be falsely explained away as a symptom of mental illness, and (2) her mental life was unaffected enough that her husband, Greg, married her after she was disabled, making it hard to think of her as less than a real person - as people with psychiatric labels ("diagnoses") typically are.

In a [letter](#) dated November 30, 1999, Jenelle writes: "Greg and I had been good friends quite a few years before I aquired TD [tardive dyskinesia]. He was one of few friends who stuck by my side during my illness and continued our friendship after I returned to school. I lost many people that I once thought were my friends after this happened to me. Greg is what a best friend really should be. He cares about me and who I am. He sees beyond my disability and always looks at me as a true partner and I look at him the same way. Greg would never stoop to pity me. He knows that I feel pity is degrading and stands up for me when I refuse to tolerate it from others. We married each other because we had an amazing friendship and we fell in love. I believe people with disabilities of any sort are no different from anyone else in their emotional needs and first of those human needs I believe is love."

Neuroleptic drugs include but are not limited to chlorpromazine (Thorazine), clozapine (Clozaril), fluphenazine (Prolixin), haloperidol (Haldol), risperidone (Risperdal), trifluoperazine (Stelazine), and olanzapine (Zyprexa). According to psychiatrist Peter Breggin, M.D. & professor David Cohen, Ph.D., in their book *Your Drug May Be Your*

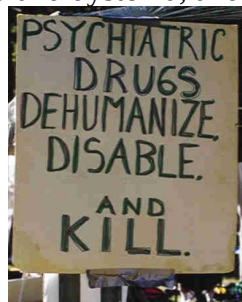
Problem: How and Why to Stop Taking Psychiatric Drugs, "Rates of TD [tardive dyskinesia] are extremely high. Many standard textbooks estimate a rate of 5% - 7% per year in healthy young adults. The rate is cumulative so that 25% - 35% of patients will develop the disorder in 5 years of treatment" (Perseus Books, 1999, p. 78). They say "Most elderly patients, treated [with neuroleptics] for only two or three months, develop obvious, irreversible twitches or spasms; they risk dementia as well" (ibid., p. 104).

Jenelle's story illustrates that U.S. Food & Drug Administration (FDA) approval is not a guarantee of a drug's safety. In his book *With Justice for None*, lawyer Jerry Spence says "If we have learned anything from nearly a century of government regulation, it is that the administrative agencies of government are almost invariably captured by the industries they are created to regulate" (Penguin Books, 1989, page 205). Or as psychiatrist Peter Breggin says in his book *Brain Disabling Treatments in Psychiatry: Drugs, Electroshock, and the Role of the FDA* (Springer Publishing Co., 1997, p. 227): "When it comes to warning about the dangers of psychiatric drugs, the FDA is more responsive to the profit needs of industry than to the safety of patients."

Despite the harm caused by neuroleptic drugs such as those given Jenelle -

- Psychiatrists not only continue to prescribe them for people but continue to *force* them on unwilling hospitalized patients.
- The U.S. Food & Drug Administration (FDA) allows the drugs to stay on the market.
- State legislatures and Congress do nothing to protect people from these harmful drugs - and in the last few years 41 states of the U.S.A. have even enacted "outpatient commitment" laws the primary purpose of which is to *force* people to take them.
- Relatives of misbehaving or "mentally ill" people such as those in the National Alliance "for" the Mental Ill (NAMI) continue to encourage and even force people in their families to "take their medicine" even when the "medicine" is a harmful drug like those Jenelle took - and to lobby for legislation to force the drugs on ever larger numbers of people.

See [Jenelle's web page](#) for more information about her, more pictures, and links to information about tardive dyskinesia and dystonia, and [A Proposal for Jenelle's Law](#).



Roberta had been treated for several years with the "miracle drugs," neuroleptics such as Thorazine, Haldol, Mellaril, and Prolixin. My medical evaluation described her condition:

Roberta is a grossly dis❖gured and severely disabled human being

who can no longer control her body. She suffers from extreme writhing movements and spasms involving the face, head, neck, shoulders, limbs, extremities, torso, and back—nearly the entire body. She had difficulty standing, sitting, or lying down, and the difficulties worsen as she attempts to carry out voluntary actions. At one point she could not prevent her head from banging against nearby furniture. She could hold a cup to her lips only with great difficulty. Even her respiratory movements are seriously afflicted so that her speech comes out in grunts and gasps amid spasms of her respiratory muscles.

Roberta's current psychotic disorder is most probably also a product of neuroleptic-induced brain disease. Her inappropriate affect—giggling and superficial smiling while in great distress—is typical of brain damage. Roberta may improve somewhat after several months off the neuroleptic drugs, but she will never again have anything remotely resembling a normal life